A DECADE OF PASSION IN ACTION:

Georgia's Brain & Spinal Injury Trust Fund Commission Celebrates 10 Years



FY2008 ANNUAL REPORT



Table of Contents

Executive Director's Letter
WE IDENTIFY: Through the Central Registry. 2 Georgia's Unique and Important Resource 2 2007 Injury Data 3
Celebrating the 10th Anniversary of the Brain & Spinal Injury Trust Fund: A Letter From Past Commission Chair, Dennis Skelley
WE ASSIST: Through the Trust Fund
WE ADVOCATE: As the Lead Agency
2008 Successes and Future Goals
State Action Plan
Stewardship
Making Noise: Ayanna Anderson, Stewardship Coordinator
Leadership Development Program. 13 Community Building. 13
10th Anniversary Celebration
Chairman's Letter
2008 Financial Information and Distribution Data
Meet Our Commissioners
Applying for a Trust Fund Award

On the Cover: Commission Member J.D. Frazier (L), like many others living with spinal cord or traumatic brain injury, is grateful for the assistance of a skilled and compassionate caregiver like Jazmin Johnson (R), who has been working with him for three years. "Jazmin is an example of the type of person who provides the kind of care that the Trust Fund is so dedicated to facilitating – the caring and confident skills and attitude that allow our recipients to live much more fully in every aspect of their lives," he says.

Funding for caregivers represents a large portion of Trust Fund award requests (see pg. 17, "Personal Support Services" award category). However, nationwide, more than 50 million people are providing "free" care for a chronically ill, disabled, or aged family member, at an estimated value of \$306 billion a year – almost twice as much as the \$158 billion actually spent on homecare and nursing home services combined. Seventeen percent of these family caregivers are providing 40 hours of care or more per week. (For data sources and more information, visit our website at www.bsitf.state.ga.us.)



Friends:

I am so proud to see the continued good progress of the Commission and its partners who provide much-needed resources for Georgians with traumatic brain and spinal cord injuries. The Commission's committees have labored intensively. Two committees produced publications: the Children and Youth Committee's *Children's Resource Guide* for families and professionals, while the Brain Injury Task Force contributed to the Senate Study Committee's report on Brain Injury Related Neurobehavioral Issues (see: www.bsitf.state.ga.us). These publications summarize the resources available in Georgia and identify where critical resources are lacking. The Distribution Committee recommended changes to our policies resulting in higher dollar awards for neurobehavioral therapy and vehicle grants, and our Advisory Committee finalized a new State Needs Assessment and State Action Plan. The Needs Assessment and State Action Plan documents the gaps in services that our public officials need to address, especially as the incidence of traumatic brain and spinal cord injuries rise. To all of our committee volunteers, I offer a humble thank you – these plans and documents would not have happened without you.

One of the highlights of the year was celebrating the 10th Anniversary of the founding of the Brain and Spinal Injury Trust Fund Commission. A moving tribute, held at the Shepherd Center in Atlanta, July 2008, featured photographs of hundreds of people who gave so much time and energy and, most importantly, devotion, to creating the first state agency in Georgia specifically charged with providing for the care and rehabilitative needs of people with traumatic injury. As you read this report, and in particular, former Chair and commission member Dennis Skelley's letter on the next page, we hope you'll appreciate just how far we've come. At the event, the Commission presented our annual Pathfinder Awards to our indefatigable Chairman Rusty Kidd, to Senators Don Thomas and Ronnie Chance, and to Representative Steve Tumlin. Our first Volunteer of the Year award was earned by Chantay Reese of Augusta, GA, who has served on the Distribution Committee for five years and brings the perspective of a survivior of traumatic brain injury (TBI). She received the Larry Huggins Memorial Award, in honor of our good friend and former Commission member who passed away last year.

The Commission has worked hard to educate our elected officials, healthcare providers and governmental agencies about the unmet needs of Georgians with traumatic injuries. We are optimistic that the future will present more opportunities for education, outreach and service. Though Georgia is buffeted by economic turbulence, we can continue to work smart, leverage our resources with like-minded local and state agencies and find new partners to help us extend our hand to more Georgians than ever.

More than 57,000 Georgians sustained a reported TBI or SCI in 2007. We estimate thousands more were not reported to the Central Registry. Times are hard right now, but they are indisputably harder for our neighbors who must adapt to a new reality postinjury. The Trust Fund Commissioners and staff are working diligently on your behalf to ensure that the necessary resources for the care and rehabilitation of our applicants are available today and in the future.

We pledge our continued best efforts.

Sincerely,

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Craig Young, BSITFC Executive Director

We Identify: Through the Central Registry

Traumatic brain injury is the leading cause of death and disability for any person age 45 or under.

Georgia's Unique and Important Resource

Prior to 1980, rural Georgians with spinal cord injuries were dying due to lack of resources and no way to connect to rehabilitative facilities. In response to this alarming situation, the Georgia Legislature established the Central Registry for Traumatic Brain and Spinal Injuries in 1981 to keep count of the number of Georgians that sustain a traumatic brain and/or spinal cord injury each year. The agency that administers **the Registry is required to contact each individual identified – a costly task for an unfunded mandate** – but one that is critically important, according to Stephanie Lotti, the Trust Fund's Director of Data and Public Policy:

"People who have been injured need to know where to go for help and what resources are available to help them recover. Without the Central Registry, they may not receive the information they need. That's why we're committed to making sure every person with an injury is counted, and every person on the Registry is contacted."

The Central Registry differs from other trauma registries in the state in a number of ways. The Central Registry collects data from every civilian hospital in Georgia, rather than just through the state's 16 trauma centers. It also includes data for people admitted to the hospital as well as those discharged from the emergency room. This is particularly important for patients with TBI, who can manifest symptoms months or years after the injury.

The Commission took on the administration of the Central Registry in 2004 and has since improved the data collection process. Our first step was to correct the severe undercount of those who had sustained traumatic injuries. In its first year of collecting data, the Commission found 45,080 new injuries, where only 2,401 had been reported the year before.



Mark Halvorsen (L) and Chantay Reese bring first-hand experience to their advocacy efforts on behalf of others with TBI. Chantay received this year's Larry Huggins Memorial Award, and according to Distribution Committee Chair J.D. Frazier, she not only brings an enlightened perspective to the committee, but is "relentless in pursuing the best interests of her peers." Mark speaks frequently and eloquently about the difficulties of veterans returning from the Middle East with TBI, and is a member of the Trust Fund's State-wide Traumatic Injury Advisory Committee.

This year, 57,790 new injuries were reported. In addition to contacting each person identified through the Central Registry, the Trust Fund uses the aggregate data to:

- better identify the needs of Georgians with traumatic injuries,
- advocate for improved services, and
- partner with other agencies to improve research and prevention initiatives.

Central Registry for Traumatic Brain and/or Spinal Injuries Data from January 1 to December 31, 2007

Total Injuries - 57,790

AGE RANGE IN YEARS	Emergency Department TBI Only	Hospital TBI Only	Hospital TBI + SCI	Hospital SCI Only
0 – 4	8,920	284	**	**
5 – 9	4,257	143	**	**
10 – 14	3,604	158	**	**
15 – 24	9,651	1,123	44	69
25 – 34	5,880	817	26	81
35 – 44	4,899	769	25	92
45 – 54	4,168	796	29	102
55 – 64	2,711	632	18	80
65 – 74	2,069	589	**	71
75+	4,277	1,268	10	53
Missing	32	15	0	0
Total	50,468	6,594	170	558

SEX	Emergency Department TBI Only	Hospital TBI Only	Hospital TBI + SCI	Hospital SCI Only
Female	22,861	2,503	46	154
Male	27,598	4,091	124	404
Unknown	9	0	0	0
Total	50,468	6,594	170	558

INJURY CAUSATION	Hospital + ER TBI	SCI
Motor Vehicle Traffic	13,934	132
Falls	13,085	106
Struck by Object/Person	8,755	**
Assault/Violence	**	40

**fewer than 10

The Central Registry shows 13,000 more traumatic brain injuries reported between 2004 and 2007 – a 29.5% increase in just three years.

Total injuries recorded for 2007 – 57,790 – is 5.6% higher than in 2006.

On our 10th Anniversary, it is my pleasure to comment on the success of Georgia's Brain and Spinal Injury Trust Fund. Our 1998 Constitutional Amendment received the highest rate of "yea" votes in the history of Georgia. Without question, this was due to the tremendous grassroots efforts of brain and spinal injury advocates of the day campaigning tirelessly with legislators and the general public to increase awareness and express that this Trust Fund was simply the right thing to do!

The Trust Fund was truly the first dedicated funding effort addressing the non-medical needs of individuals with brain or spinal injuries who were gallantly trying to live independently in their own communities. The fund is not and never was a substitute for Medicaid, but rather a new and separate funding source designed to assist with or pay for services and items that would allow individuals with brain and spinal injury to sustain independent living.

Early on, Commissioners and staff worked diligently to define operational and distribution policies; collect funds; identify needs; and gain day to day knowledge of how the Trust Fund would work with state government. It is important to acknowledge the Commission members for working many, many hours hand in hand with staff to get the job done.

An initial success was the Trust Fund's adoption and management of Georgia's Central Registry for Traumatic Brain and Spinal Injuries. The Registry now provides credible data to be used with policy development, research, and grant funding. Other successes include a partnership with the Department of Labor's CreditAble Program, offering low-interest loans to persons with SCI and/or TBI for assistive technology devices; and the partnership with the Area Agency on Aging and the expansion of the Gateways initiative, whereby 17,000 statewide resources for people with long term care needs now include specialized listings for persons with TBI.

The Trust Fund has played a strong role in bringing the right people to the table to facilitate system change. Meetings across the state have not only increased awareness of the Trust Fund but have also encouraged Georgians to be involved in the Trust Fund's Advocacy Network. Additionally, the recommendations of the Children and Youth subcommittees have assisted in the creation of a State Action Plan as well as several other initiatives including web-based training on TBI for teachers through the Department of Education and the authorship and distribution of a TBI fact sheet and adult and children's resource guides.

The Commission's recent white paper addressing Georgia's neurobehavioral crisis associated with TBI led to the creation of a 2008 Senate Study Committee led by Senator Don Thomas. Not only did this provide a terrific opportunity to increase legislators' awareness of the committee, but it also allowed for new initiatives to move forward very quickly. Already, Commission members, Trust Fund and Department of Community Health staff, and Georgia Medical Foundation representatives have formed an ICWP Advisory Committee. In addition, meetings with Public Health Officials regarding Birth Outcomes are underway with a goal of supporting a single point of entry for children with TBI through Children 1st. Those familiar with TBI and SCI recognize just how important change is in both of these areas.

The accomplishments of the past 10 years show that understanding is increasing and positive changes are being made – and advocacy for this change has not withered but grown stronger. The Commission and staff recognize their work is important and should be encouraged and motivated to endure. Change is everywhere and ensuring that Georgians with SCI and/or TBI are at the table is an exciting task.

Sincerely,

B.8

Dennis B. Skelley PT, MSA, FACHE President/CEO, Walton Rehabilitation Health System Past Chair and Commission Member

CELEBRATING THE 10TH ANNIVERSARY OF THE BRAIN & SPINAL INJURY TRUST FUND



"...our 1998 Constitutional Amendment received the highest rate of 'yea' votes in the history of Georgia."

We Assist: Through the Trust Fund

Ten years ago, a handful of determined Georgians struggling to resume their active lives after suffering traumatic brain injuries discovered that no funds existed in the state to help meet their needs. Their immediate medical care had been covered through insurance or Medicare/Medicaid, but it was difficult to fully integrate into their communities without things like wheelchairs, accessible home modifications, vocational training, and other necessary tools not covered by insurance. Other states had money set aside for this purpose, but Georgia had nothing. Something needed to be done.

Partnering with organizations like the Brain Injury Association of Georgia, Shepherd Center, and local brain injury support groups, these grassroots activists lobbied the Georgia General Assembly for their cause. After years of hard work, legislation finally passed to create the Brain and Spinal Injury Trust Fund – a critical source of funding for the long-term needs of people with traumatic brain and spinal cord injuries.

In the 10 years since this personal and legislative battle was won, the Trust Fund has distributed more than \$10 million to help more than 3,100 people with traumatic injuries to pursue lives of meaning, independence, and inclusion. This year, 308 Georgians were awarded a total of \$1,976,437.32. Though the average award was less than \$6,500, these funds provided the springboard necessary to help hundreds of people "My job is to keep up awareness until adequate funding is found for people with TBI." ~Waring Jackson

improve their lives. (see pg. 17 for a breakdown on how the Trust Fund awards are distributed).

Because our budget – funded through a surcharge on DUI fines – is not keeping pace with the need, we are relying more than ever on our partners to extend our mission. Whether you're a care giver, family member, or person with an injury, please consider giving back to the Trust Fund. Your advocacy and volunteer efforts are necessary to sustain the Trust Fund.

Just ask Waring Jackson. His world changed when he learned his mounting problems were due to an undiagnosed TBI. Since then, he's done all he can to advocate for others like himself, including serving on the Trust Fund's Leadership Development Program (see pg. 13). His advocacy efforts, in tandem with the Commission, give voice to people who need help most. We need more people like Waring on our team so more can be accomplished for Georgians with traumatic injuries.

If you, or someone you know, could benefit from a Trust Fund award, please contact our office or visit our website to start the application process. If you'd like to advance the cause of people with TBI/SCI, please let us know. Everyone has a role to play at our organization.

HISTORICAL TIMELINE 10 Years of Serving Georgians with Traumatic Brain and Spinal Injuries.

1995

BIAG board member David Goudelock chairs committee to lobby for creation of a Brain and Spinal Injury Trust Fund to provide financial assistance for Georgians who have sustained traumatic brain and/or spinal cord injuries.

1997

A grassroots coalition of organizations, individuals, and advocates in the TBI/SCI community lobby the Georgia legislature for the creation of the Trust Fund. Opinion polls show overwhelming public support for funding the Trust Fund through a DUI surcharge.

1998

SB 110 creates the Brain and Spinal Injury Trust Fund, and is ratified by an overwhelming 73% of voters during the November general elections. The General Assembly establishes a 15-member Authority to act as the Trust Fund's board of directors.

Waring Jackson: From Recipient to Leadership

WARING JACKSON WAS HOURS FROM

ATTEMPTING SUICIDE. Despite a loving family and an impressive resume, the 43-year-old photog-<mark>raphy professional couldn't go on. He had endured</mark> "three years of hell": losing his friends, his job, his patience, and his memory.

"My wife was livid because I'd leave my office at five and not get home until 11," he recalls. "I just couldn't find my way home."

No one connected Waring's increasingly odd behavior to the concussion he received when thrown from his motorcycle three years earlier. During a weekend camping trip, the lifelong motorcyclist had slipped on a wet mountain road.

"I was going 25 mph when I was launched 50 feet in the air," he says. "Nothing was broken but grand mal seizures landed me in an Asheville trauma unit."

After two weeks, he appeared well and was released. Then his life began to unravel.

"I kept struggling to be the man I had been," he says. Growing up he had used humor to hide his dyslexia. He tried the same approach to smooth increasingly difficult social situations. But he had no remedy for being confounded by junk mail, overwhelmed by noise and experiencing a reading level that declined to second grade.

Only after his wife Jane foiled his suicide plans and took him to Emory for a psychiatric evaluation, did they receive the crucial piece of the puzzle: severe traumatic brain injury.

"I knew he was suffering, having a breakdown, but I didn't know from what," remembers Jane, who had never heard of brain injury. "After his diagnosis, everything came together."

Unfortunately, Waring's experience is fairly common for Georgians living with an undiagnosed brain injury, according to scores of studies conducted by health care professionals.

"TBI means one day you die and you wake up a new person," he says. "It's as if there's another soul in you speaking - and you may not even like that person."

Waring's ability to articulate his situation makes him a compelling advocate for people with TBI. As a participant in the Trust Fund's Leadership Development Program (LDP), his perspective has been especially helpful to the Distribution Committee as it seeks to give more awards to people with TBI. According to Wendy Butts, Director of Planning and Review, Waring's perspective, " ... educates the committee members about traumatic brain injury in ways that we could never understand. It sheds a unique light regarding the difficulties that Georgians with TBI struggle with everyday. Waring challenges us to think outside the box of what is necessary, and therefore possible, for the full independence of persons with TBI."

"Our drop in income has been one of the nightmares of this injury so I understand what the needs are," he says, adding Trust Fund awards for a GPS navigation system and counseling sessions have been critical to his rehabilitation.

After many false starts with psychologists untrained in TBI, the couple found one of the few neuropsychologists (he says there are less than a dozen in Georgia) who could help them understand and manage new personality traits that stress their marriage, such as angry outbursts and persistent napping.

In addition to neuropsychological counseling, Waring cites reliable transportation, GPS navigational systems, innovative therapies, and support services as priority items for people with TBI. He also stresses that funding for recreation and social opportunities should not be considered superficial, but fundamental to addressing the isolation and depression that results from the injury.

1999

A 10% surcharge on DUI fines begins to fund the Trust Fund.
The first Authority members are sworn in by Governor Roy Barnes.

2000 SB 480 is passed, ensuring that all courts in Georgia contribute the surcharge on DUI fines to the Trust Fund.

2001

The legislature appropriates \$150k to the Trust Fund for administrative support and implementation.

2002

SB 364 changes the Authority to a distributions to 57 applicants are approved on Dec.17.

2003

Beginning its first year of full-time operation, the Commission travels to nine cities to gather input from individuals, care givers, advocates, and service partners on the most effective uses for the Trust Fund. \blacklozenge The Department of Community Health requests BSITFC to assume the role of Lead Agency for TBI services

Development Program

After helping the Trust Fund with everything from moving offices to evaluating its award application, he's enjoying his new role on the LDP, as he says, "learning strategies to effect change."

Ten years after his accident, Waring is a creative, determined powerhouse despite no short-term memory and limited reading and writing skills. He attributes his positive outlook to his involvement with support groups and organizations working on behalf of people with TBI.



Wearing his homemade buttons, Mardi Gras beads and a headband in blue – the signature color of brain injury – Waring Jackson (L), stands with GA State Representative Sean Jerguson outside the Capitol steps on Disability Day.

"Working for the Brain Injury Association of Georgia (BIAG) has awoken his ability to be an advocate," says wife Jane, who has a part-time paid position with the organization, but who often works up 60 hours per week on behalf of the nonprofit. "He found a niche where he can make a difference." Disability Day is one of the events that galvanizes Waring's abilities – both promotional and photographic. After attending the demonstration at the Georgia capitol, Waring decided people with TBI needed to be more visible.

He began with buttons. Creating inspirational phrases like "Never, Never Give Up" and "Happiness is a Choice" on 45 different buttons, led to head bands, kazoos, balloons, and Mardi Gras beads in the vibrant blue used as the official color of brain injury. Waring says even if you can't attend the event, you have a role to play.

"You may not be able to drive, but, by golly, most of us have access to a legal pad, envelope and a stamp," says the man who started a statewide letter writing campaign last year. He posted details on how to contact elected officials on the BIAG website to encourage others to get involved.

"You've got to tell elected officials that you're here," he says. "Tell them we don't want a hand out, but give us a helping hand."

For Waring, this means advocating for innovative solutions. An idea he calls the "Waring House," proposes utilizing empty big box spaces by mixing small business with nonprofit housing for people with disabilities. He's optimistic that this idea, among others, may gain traction now that he's on a first name basis with his senators. Again, he attributes this access to his willingness to lend a hand.

"I asked the candidates, 'what can I do to help?' when they were campaigning. I folded letters, stood on street corners, did the boring work, but then I got to sit with candidates and share my story. Now they know who I am."

Waring is relentless in his pursuits and encourages others to adopt a similar approach, regardless of what their perceived abilities are.

"My job is to keep up awareness until adequate funding is found for people with TBI," says Waring.

in Georgia. The Commission expands the role to include SCI services. ◆ The Trust Fund awards \$810,655.

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2004

The Commission begins administrative management of the Georgia Central Registry for Traumatic Brain and Spinal Injuries, in accordance with SB 582, and identifies 45,000 new traumatic injuries, compared with 2,400 identified the year before under the previous administration. The Trust Fund awards \$1,061,742 to 252 recipients.

2005

Within one year of the Commission's management of the Central Registry, more than 51,000 new incidences of TBI and SCI are identified. • The Commission awards almost \$2 million to 523 recipients, and by June of 2005 total awards reach the \$3.5 million mark.

We Advocate: As the Lead Agency

Public Policy

For 10 years, the Commission has not only distributed funds to help people with TBI/SCI cover their rehabilitative needs, we've also worked tirelessly to support public policy changes that make a difference in the lives of people with traumatic injuries, reduce the number of traumatic injuries each year, and improve the state's system of services for people with TBI and SCI.



Senator Don Thomas (middle) has been a strong advocate of the Trust Fund, sponsoring the Senate Study Committee on Neurobehavioral Issues. (Pictured here with Commission Chair Rusty Kidd (L) and Commission Member David Renz.)

Legislative Success

As the state's Lead Agency on Traumatic Brain and Spinal Injuries, we address critical issues on the state and federal levels. Each year, the Commission develops a public policy agenda and invites public comment to help guide priority issues during the legislative session. In 2008, we advocated for the establishment of a Senate Study Committee on Neurobehavioral Issues – recommended in our 2007 white paper, "Georgia's Neurobehavioral Crisis: Lack of Coordinated Care, Inappropriate Institutionalizations." We were successful!

The Study Committee, led by Sen. Don Thomas (R-Dist. 54), met four times between August and December 2008. Meetings reviewed the major recommendations of the white paper, including:

- Screening and Identification;
- Training and Awareness;
- Rehabilitation; and
- Long-term or lifelong supports.

Too many families are torn apart and financially burdened because of unnecessary institutionalizations. Implementing a proper system of care will improve our communities and provide appropriate care for those with TBI-related neurobehavioral issues.

2006

In September, the Commission holds its first SCI Summit in Atlanta, GA. Thirty-three leaders from the SCI support community gather for networking and education. The Commission is awarded a \$100,000 Health and Human Services HRSA traumatic brain injury implementation grant for three years. • Collections of the DUI surcharge decrease, so new measures are sought to make sure the Trust Fund is adequately supported.

2007

More than 2,000 Georgians have received \$8.8 million in Trust Fund awards in the Commission's five years of disbursements. The Commission compiles a white paper, Georgia's Neurobehavioral Crisis: Lack of Coordinated Care, Inappropriate Institutionalizations,

Looking Forward

In addition to supporting the Senate Study Committee, we're supporting efforts on seat belt legislation, which, if passed, would eliminate exemptions from seat belt requirements, and could drastically reduce the number of traumatic injuries resulting from vehicle accidents. Additionally, we will:

- Continue to monitor factors affecting the collection and distribution of court fines and fees, which fund the Trust Fund.
- Evaluate any changes to Medicaid waiver programs, and the impact these changes might have on Georgians with TBI/SCI.
- Support additional funding for waiver programs, including Unlock the Waiting Lists.

On the federal level, we will continue to monitor and support the passage of the Christopher and Dana Reeve Paralysis Act, the Community Choice Act, and the Workforce Investment Act.

State Action Plan

After five years of intensive work with many partnering agencies, the Commission issued a Needs Assessment

and State Action Plan on the services available for Georgians with brain and spinal injuries in July 2008. The report details the needs of Georgians with TBI/SCI, evaluates services, and proposes seven initiatives to improve these services, including:

- Educate state agencies and elected officials about the incidence, needs, and specialized service models for Georgians with brain and spinal injuries;
- Secure adequate and specialized funding, and a single point-of-entry to the service system;
- Improve medical and rehabilitative care, health and wellness, and access to school services;
- Enhance support for people with brain and spinal injuries, their families and caregivers;
- Identify and screen additional people with brain injuries;
- Facilitate independent living and community participation; and
- Reduce the incidence of brain and spinal injuries among Georgians.

The Commission will work in the coming year to spur implementation of these initiatives to ensure that the best resources the state has to offer are available to Georgians with traumatic injuries.

As with all other aspects of the Trust Fund, the Commission needs your action and support to advance our public policy goals. You don't have to be a seasoned advocate to make a difference! Just sharing your story can be the most effective means of instigating change. If you'd like to be involved in our advocacy efforts, please contact us. To learn more about our legislative priorities, see: www.bsitf.state.ga.us.

that generates media coverage around the state. The Central Registry reports more than 53,000 Georgians treated for TBI and/or SCI in the state's hospital or emergency rooms in 2006.

2008

The Commission celebrates its 10th Anniversary with a tribute and recognition reception at Shepherd Center. Chantay Reese is awarded the first Larry Huggins Memorial Award for her contributions serving on the Distribution Committee. • Trust Fund awards surpass \$10,000,000. • The Trust Fund issues its new state-wide Traumatic Brain and Spinal Injury Needs Assessment and State Action Plan report for the state of Georgia. The Georgia Senate Study Committee for Neurobehavioral Issues convenes hearings in Atlanta based on the Trust Fund's white paper report.

Passion for the Possible: Mark & Susan Johnso

MARK JOHNSON IS A BORN RABBLE-ROUSER.

Full of fire, he fidgets with impatience during long meetings. He'd rather do something – anything – than sit around and talk. It's this passion for action that makes him one of the nation's leading disability advocates.

"Everything is a community organizing opportunity to me," he says. As Director of Advocacy at Shepherd Center, his excitement is palpable at each new chance to "stir and connect" – his words for building a coalition of grassroots advocates around a common cause: "Oooh!" he'll exclaim, "Four people have called me about that! Maybe it's time to connect them or create something around that!"

In more than 30 years of stirring and connecting, Mark, who acquired a C5-6 spinal cord injury in a diving accident in 1971, has made a significant impact on the opportunities and resources available for people with disabilities, and garnered him state and national recognition. Adding to a slew of previous honors, he was recently inducted into the National Spinal Cord Injury Association's SCI Hall of Fame and received the Henry B. Betts Award from the American Association of People with Disabilities. In December 2008, the Georgia Hospital Association presented him with the Hospital Heroes award.

But even with a career full of accolades, Mark says he's proudest of his faith and family. "Faith gets me up every day and lets me sleep every night," he says.

And the proud father can't pass up a chance to brag. "We celebrated Lindsey's second year of teaching first grade," he beamed. "She's just becoming a beautiful person," Mark says. "When you look at that stuff, you go, 'She made choices, but hopefully Susan and I and other people that cared about her gave her some grounding.'"



His voice carries a similar mix of nostalgia and hopefulness when he talks about the early days of the Commission.

"The campfire story," he says with a hint of pride, "is that I had to lock everybody in a room until they made decisions." He laughs, then backpedals sheepishly. "It was almost that, but you know, it's been embellished a bit." Ten years later, he's still hawkishly committed to making sure the Trust Fund maintains its original intent: "that individuals are capable of identifying what they need, and when they do, we support them," he says.

"If we as a society can figure out how to embrace and support even the most severely disabled people, then we'll finally be there – *nirvana*," Mark says. "But it takes a lot of figuring out; it takes a lot of hard work. It's like that quote, 'Hope is passion for the possible.' We have to move away from this idea that disability doesn't happen to many people. We have to move away from thinking 'it's their problem, not mine,' and start embracing community and all the differences that make it a community."

"That's a lot for people to think about, but hey," he says, already impatient with his own philosophical waxing, "just embrace the lifestyle and get on with it. It's a lot of fun!"

Conversation with Susan Johnson Vice Chairperson, BSTIFC and Director of Brain Injury Services at Shepherd Center

What can you say about the evolution of BSITFC? We've come a long way baby! Decisions are made faster. More experts are involved. Our subcommittees have people on them that know the issues.

What are your proudest accomplishments with the Trust Fund? I'm proudest of participating in the development of the white paper last year called, "Georgia's Neurobehavioral Crisis: Lack of Coordinated Care, Inappropriate Institutionalizations." This report was compiled by a broad group, including families experiencing neurobehavioral problems and dedicated health professionals. The ensuing media coverage about the crises caused by lack of services helped us get a legislative study committee to look at the issues in-depth (see pg. 8). Although budget cuts will impact the committee's recommendations, we've begun seeking collaborative relationships with other state agencies to do what we can to improve services.

on Work Tirelessly for Change

IN THE BEGINNING, MARK AND SUSAN

WERE CO-WORKERS. She was an ambitious speech pathologist interning at a rehabilitation hospital in Charlotte, NC. He was a counselor there for people with spinal cord injuries.

A self-described "intense, hard worker," romance was the last thing on Susan's mind. "When he asked me out, I freaked," she remembers. Never having dated a guy in a wheelchair, Susan was unsure how to proceed. Yet, as she looks back over their happy 28-year marriage, what drew them together seems obvious – both are passionate about their work; both are independent thinkers; both love a good reality TV show.

Mark's legendary charisma had claimed another prize. It is a trait that served Mark well as he became, in Susan's words, "a radical." She credits his van getting totaled – and the eight long weeks it took to get it repaired – as the starting point. Mark had to depend on Susan and buses for transportation.

Soon after, she picked up the morning paper and received a shock.

"There was Mark on the front page, handcuffed to a railing, protesting for more accessible buses," she exclaims. "I was really proud of him. I understood what it meant not to have reliable transportation."

This personal experience, combined with professional expertise, has forged Susan's own brand of activism, especially on behalf of people with traumatic brain injury. Over the course of nearly 30 years, her work as a clinician led to developing Atlanta's first day treatment program for people with brain injury, then directing services at several rehabilitation hospitals.

Today, as Director of Brain Injury Services at Atlanta's Shepherd Center and as vice chair of the Trust Fund, Susan is passionate about addressing the huge gaps in services for people with TBI. She has been instrumental in spearheading the Trust Fund's white paper on neurobehavioral issues and recommendations for its State Action Plan.

"I think taxpayers would be appalled if they really understood that Georgians who experience neurobehavioral problems are not receiving appropriate and timely care. This results in an exorbitant amount of unnecessary costs to this state and to their hard earned dollars. Families are heartbroken and face bankruptcy to get care and support for their loved one," she says.

"Families are heartbroken and face bankruptcy to get care and support for their loved one."

When her frustration over the lack of needed services threatens to boil over, she doesn't look far for inspiration.

"It helps me to think about how long Mark's been working on issues like architectural change, personal support services, transportation," she says. "Even so, I don't want it to take that long; I'm more impatient!"

As the conversation shifts to Mark's attributes, Susan's voice softens.

"Mark's a great dad. He was voted best coach of the year in Alpharetta for coaching our daughter's high school softball team," she says "The girls loved him; they all wanted to be on his team because he wore silly cowboy hats and drove them to win."

In the end, Mark and Susan's shared tenacity and complimenting abilities have made them a powerful force. Once again, they are co-workers, but as partners in spirit, they are forging an extraordinary path.

What do you wish more people knew? It's incredible to me how few people know about how many of us suffer from a brain injury or understand its lifetime consequences. In this state alone there are more than 50,000 new injuries a year. More than 6,000 of these injuries require hospitalization, which means people have a moderate to severe injury that will affect their lifestyle and dreams.

Brain injury affects not only the injured person but their families and close friends. It often bankrupts families because health care coverage for rehabilitation and long term care is limited or non-existent. Many insurance companies do not pay for cognitive rehabilitation. That is shameful considering how much these folks can offer to our communities.

What do you want for the future for the Trust Fund? The Trust Fund needs to be funded the way Mental Health and other health services are funded by the state. In the meantime, the Commission is seeking more collaborative partnerships with state organizations, like Children's Services and Department of Aging, to extend our limited funds.

Stewardship

Stewards are essential to the success of the Brain and Spinal Injury Trust Fund Commission. Stewards broaden our reach, sustain the Trust Fund and enrich us with fresh perspectives and expertise. Our Stewardship Coordinator Ayanna Anderson is passionate about building communities of support for the Trust Fund. That's why she spent the past year meeting with all the community independent living centers in Georgia as well as with staff at rehabilitation hospitals, support groups and veterans.

Stewards to help people (especially those with TBI) with the Trust Fund application process are needed; however, if you'd like to contribute in other ways, let us know.

Ayanna Anderson: Making Noise Across the State

WHEN THE COMMISSION PROMOTED HER AND TOLD HER TO HIT THE ROAD, AYANNA ANDERSON KNEW SHE WAS ON THE RIGHT TRACK.



The vivacious former New Yorker says being on the "front lines" is where she wants to be. In fact, that's where she thrives.

"I'm out most of the week giving presentations, asking as many people as I can, 'Do you know anyone who needs our services?'" Each month her efforts introduce hundreds of people, with new and older injuries, to the Trust Fund's resources.

In Ayanna's meetings with organizations across the state about Trust Fund grants, she educates nurses, hospital case managers, therapists, social workers, community independent living service staff – "anyone who will listen" – to facilitate the application process.

Ayanna attributes her success to humor and pithy presentations: "I keep it short, always under an hour."

Elizabeth MacDonald, Rehab Services Community Educator at Atlanta Medical Center agrees.

"Ayanna gave us a thoughtful, organized and funny presentation. I liked that she was very honest about what the Commission can and can't do." MacDonald, whose facility handles many brain injuries, says there is great need for more services. "What we liked about the Commission is that it's different; it provides a wider scope. Instead of just providing a wheelchair for a doctor's appointment, the Trust Fund gives what's needed to get back into society."

Challenging Support Groups

Injury support groups tend to be Ayanna's most vocal audiences. Complaints about lack of funding for people with injuries often come from those who are eager to return to work.

"I share their frustration," says Ayanna. "I remind them it's a competitive grant and a lot of people are in need, and that we're only one of several state agencies that depend upon DUI fines for funding." Then she turns it around.

"I ask, 'What have you done to increase funding?' The Commission came into existence because concerned Georgians made noise, so I ask support groups, 'Have you been making noise?' I know they're frustrated, but you have to make noise." To help raise the volume, she hands out tips on how to contact elected officials and encourages everyone to make themselves heard.

Know a group that would like more information about the Trust Fund? Need a speaker or exhibitor at your conference or meeting? Want to arrange an online webcast? Contact Ayanna Anderson at 404-825-1466 or by email at alanderson@dhr.state.ga.us.



No surprise – Trust Fund Commission Chair Rusty Kidd gets Jackie Wilks-Weathers (Credit-Able) and Ayanna Anderson (Trust Fund Stewardship Coordinator) laughing.

Leadership Development Program

The Leadership Development Program (LDP) is an opportunity to contribute to the disability community, while building new skills and connections for yourself. Four candidates are selected for the two-year training program. Upon completion of their term, program members may be recommended to the Governor to serve as Commission members as openings become available.

Participants can work on Commission Committees that include:

Advisory: Develop policy recommendations to enhance statewide infrastructure for people with traumatic brain and spinal injuries.

Appeals: Review all timely appeals of denials.

Communications: Guide outreach efforts.

Distribution: Ensure that funds are distributed according to policy.

Finance: Ensure good fiscal management of the organization.

Nominations: Assess the work of the Commission and make recommendations for improvement.

Public Policy: Develop annual public policy agenda, monitor issues and increase the Commission's involvement in policy-making arenas.

If you or someone you know is interested in joining the LDP, let us know.



Bill Lee, Tom Connelly, and Charles Lamb share a laugh at the 10th Anniversary Celebration. All three graduated from the Leadership Development Program in 2008, readying them for potential service on the Commission. Lamb chairs the Appeals committee; Lee and Connelly serve on BSITFC's State-wide Traumatic Injury Advisory Committee. Current members of the LDP are Waring Jackson, Patricia Underwood and Lee Wallace (not pictured).

Community Building

As the state's Lead Agency on Traumatic Brain and Spinal Injuries in Georgia, we're not only supporting policy changes that benefit those with traumatic injuries, we're also building partnerships throughout the community to better extend the reach of our services. The more connected the network of services for people with TBI/SCI is, the more coordinated and holistic the care will be. That's why, in 2008, we developed strategic relationships with the following organizations:



Alana Shepherd, Co-founder of Shepherd Center and this year's Keynote Speaker for BSITFC's 10th Anniversary Celebration.

Department of Public Health, Office of Birth Outcomes/ Children 1st, working to provide a single-point-ofentry for services for Georgia families with children age 0-4 that have a TBI, and Children's Medical Services to provide medical services and post-acute care to children age 0-4 with TBI.

Department of Community Affairs (DCA), Georgia Home Access Program, to provide funding (through the Trust Fund) for safe and appropriate home modifications (through DCA) for persons with TBI and SCI.

Governor's Office of Highway Safety, Strategic Highway Safety Plan, to collaborate on the prevention of motor vehicle crashes – the highest source of injury for traumatic brain and spinal cord injury in Georgia in 2007.

Brain Injury Association of Georgia Peer Visitor Program, to provide trauma centers and hospitals statewide with our *Go Ahead, Ask* booklet – particularly to economically vulnerable patients – as well as distributing several thousand copies of our *Children's Resource Guide* to our state's Department of Education. The Commission also helped support the Information and Referral Specialist at BIAG.

Georgia Department of Education, Georgia Project for Assistive Technology, Division for Special Education Supports, to improve TBI awareness.

Georgia's Army National Guard, to combine military and community resources on behalf of injured military personnel and their families. There's a new section on military resources at our website: www.bsitf.state.ga.us.

10th Anniversary Celebration

To celebrate the Trust Fund's 10th anniversary, the Commission teamed up with some of our longtime friends in the community – Shepherd Center and R&R Mobility – to host our annual meeting and anniversary celebration. Attendees toured Shepherd Center and participated in our annual Pathfinder Awards reception. This year also marked the inaugural Larry Huggins Memorial Award for Outstanding Committee Member, in memory of the long and faithful service of our colleague and friend, Larry Huggins.

Pathfinder Awards: Rusty Kidd, The Fuller Family (Ben, Charles and Kay), Senator Don Thomas, Senator Ronnie Chance, and Representative Steve Tumlin

Larry Huggins Memorial Award: Chantay Reese

Leadership Development Program: Tom Connelly, Charles Lamb, and Bill Lee

Outstanding Service Awards: Former Commission members Zelphine Smith-Dixon, Judy Hagebak, Hunter Hurst, John O'Connor, Michael Smith, and Keith Sorrels



Commissioner Susan Johnson (middle, back row) and Executive Director Craig Young (right, back row) present Charles, Kay and Ben Fuller with a Patherfinder Award.



Commissioner David Renz (at right) presents Senator Don Thomas with one of this year's Pathfinder Awards. Sen. Thomas led the Senate Study Group on Neurobehavioral Issues – recommended in our 2007 white paper, "Georgia's Neurobehavioral Crisis: Lack of Coordinated Care, Inappropriate Institutionalizations."



Former Commission member Keith Sorrels (middle) receives an Outstanding Service Award from Commissioner Annette Bowling (R) and Executive Director Craig Young (L).



Volunteer Chantay Reese (at podium), who serves on the Commission's Distribution Committee, received the first Larry Huggins Memorial Award for Outstanding Committee Member. The award is named in honor of longtime Commissioner Larry Huggins, who passed away in 2008. Presenting the award is Commissioner and Distribution Committee Chair Joseph Frazier (front, left).



Susan Johnson gives a tour of the Brain Injury Unit at Shepherd Center prior to the start of the annual meeting and celebration.



Gary Ulicny, CEO of Shepherd Center, addresses the crowd about the importance of unity of purpose and its ability to accomplish great things – like the Trust Fund.



A full auditorium of advocates and supporters - more than 150 - attended the festivities in July.



After sustaining a TBI that left him in a coma for three months, 2008 Pathfinder Award artist Allen London's commitment to using his gifts intensified, and his purpose came into focus – "to do something for people that have had incidents like myself and to show what God can do."



L-R: Leslie McNely, John & Casey Hagadorn, and Pat Underwood celebrate the Trust Fund's 10 years of supporting Georgians with traumatic injuries.



Dr. David Burke, Director of Emory University's Rehabilitation Hospital, and Trust Fund Executive Director Craig Young visit at the Shepherd Center facilities.

"...there has been a 29.5% increase in the number of persons with traumatic brain injury – 13,000 more injuries between 2004 and 2007."

Dear Friends:

The stories you read in this report touch upon the issues that persons with disabilities encounter and overcome. The Trust Fund is working hard to mitigate these challenges. For example, Trust Fund grant award amounts were increased for non-van vehicles and for neurobehavioral services (see next page) – demonstrating the Commission's awareness of and responsiveness to the care and rehabilitative needs of Georgians with traumatic brain and spinal cord injuries.

Regarding legislative matters, the Trust Fund supports Trauma Center funding for Georgia because Georgians deserve the best possible health care. Stabilizing an accident victim is imperative; a fully functioning trauma care network will do that. However, we must not forget that after the acute care phase of treatment is completed, recovery begins. For some, the recovery phase can last a lifetime. That's where the Trust Fund comes in. Resources to support long-term care are increasingly harder to obtain. Trust Fund dollars cannot stretch as far as needed. Other avenues of funding must be found to help the rising number of injured Georgians after their discharge from a hospital.

Our Central Registry shows that there has been a 29.5% increase in the number of persons with traumatic brain injury – 13,000 more injuries between 2004 and 2007. As our state population grows, our funding must do likewise. **I've called on the legislature to add additional surcharges to violations like reckless driving so the Trust Fund will have more resources** for wheelchairs, home modifications, and personal support services – just a few of the many requests we receive each week. Given that the average Trust Fund grant is \$6,400, it should come as no surprise that hundreds of requests for awards each year are drawing down our reserves. In addition, we hope to have a bill in the legislature to allow us to actively solicit donations from the public to help raise funds.

The Commission and our staff are dedicated to providing the resources necessary for our citizens who face devastating injuries. We are in it for the long haul. With your support we can find the resources, both human and material, to make a world of difference.

E Culus Mesta

Rusty Kidd, Chair



Francial Information & Distribution Data FY2008 (7/1/07-6/30/08)

Over the past 10 years, the Trust Fund has awarded more than \$10 million and 3,109 awards to Georgians with traumatic brain and/or spinal injuries. This year, more than 300 Georgians with TBI/SCI benefited from \$1,976,437 in Trust Fund distributions. That's an average of less than \$6,500 per award, but it makes an enormous difference in the life of a person with an injury.

Evolving Policies for Changing Needs

In response to applicant requests, the Distribution Committee began allowing higher-dollar awards for neurobehavioral therapy and transportation goods and services. Transportation grants are always the top request and this year was no different, comprising 64% of total grants made. These requests span accessible or adaptive vehicles, taxi service, or other arrangements that helps a Georgian with disability remain mobile in the community and return to work. Home modifications – this year's second largest award category (14%) – also remain a constant need; they include: ramps to make homes accessible, lowered counter tops, or roll-in showers.

Collections Decreasing Relative to Prevalence

The Trust Fund is the only money Georgia specifically sets aside for the rehabilitative care of people with traumatic

TBI/SCI. It's funded through a surcharge on DUI conviction fines, which this year totaled \$2,069,640 – of which approximately \$80,000 were past-due collections from FY2007. This money covers both Trust Fund awards and our daily operating expenses.



Awards by Region since 2004 (in dollars)

Region	2004	2005	2006	2007	2008
1	114,370	154,835	289,303	225,454	174,972
2	129,952	145,597	202,432	173,985	95,338
3	532,250	648,105	989,027	904,254	719,254
4	175,183	142,831	279,793	270,354	148,104
5	95,691	176,370	283,176	226,408	200,409
6	168,082	162,938	183,792	167,701	160,922
7	18,540	66,630	29,296	84,948	74,039
8	78,554	79,689	165,759	128,195	126,659
9	76,214	95,382	187,303	193,071	149,838
10	102,483	100,319	1 <i>5</i> 0,800	133,095	126,901

Maintaining the delicate balance of preserving the viability of the Trust Fund while providing as many grants as possible has been difficult. This is especially true as more Georgians than ever are being admitted to emergency rooms or hospitals with traumatic injuries. Because our reserves are strained and collections aren't keeping up with demand, we were forced to grant fewer than half the awards and one-third the dollar amount as in FY2007 (see Awards by Region chart below for more detail). Increasingly, Trust Fund grants must be prioritized for 1) Georgians who have significant disabling injuries and 2) those who have never received a Trust Fund award.

In 2007, the number of reported traumatic injuries rose 5.6% over the previous year – **reported injuries have increased by almost 30% over the past three years as Georgia's population steadily rises**. In the coming years, we also expect to see additional requests for support from veterans of the wars in Iraq and Afghanistan. Demand is rapidly outpacing our resources.

Our Commitment Continues

Even while tightening our belts in the wake of a slimmed budget, our commitment to providing excellent service to Trust Fund applicants and advocating on behalf of Georgians with TBI/SCI hasn't wavered. We continue to:

- reach out to those identified in the Central Registry (see pg. 2-3);
- foster citizen advocates (see pg. 12);
- partner with others in the community (see pg. 13);
- promote legislation that increases independence for people with disabilities and reduces the incidence of traumatic injuries (see pg. 8-9); and
- respond to the needs identified by our applicants to guarantee that Trust Fund awards are meaningful and effective.

In the coming year, we will monitor the collections process and our cash reserves, and investigate new ways to increase funding for the Trust Fund – ensuring that we are the best stewards of Georgia's only state resource for people with TBI/SCI.

Award Summary by Category

	FY2008	FY2004-08
Transportation	\$1,269,154	\$4,012,148
Home Modifications	\$271,406	\$1,540,138
Personal Support Services	\$193,384	\$1,289,725
Assistive Technology	\$60,418	\$850,744
Durable Medical Equipment	\$36,188	\$402,411



Meet Our Commissioners

Our Commission Members are a dedicated, diverse group of individuals from around the state. Each one is committed to improving the effectiveness of the Trust Fund by overseeing its operations and disbursements.

The Governor appoints 15 members for two-year terms, although many of our members choose to serve longer. To ensure a breadth of experience and opinion, the Commission consists of: four individuals or family members with traumatic brain injury, four individuals or family members with spinal cord injury, and representatives from medical professions and relevant state agencies.

Annette Bowling (1) has been serving on the Commission since the Governor appointed her in 2000. She is the Executive Director of the Albany Advocacy Resource Center and is also involved with the Georgia ARC Network and the Commission on Mental Health/Mental Retardation/Substance Abuse. She has served on the Georgia Rehabilitation Advisory Council, the Georgia Department of Medical Assistance Consumer Advisory Committee and many other boards.

Mary Alice Bullock (2), Secretary, was appointed to the Commission by the Governor in 2006. Her son, Ben, was injured in a vehicle accident in 2004 and sustained both TBI and SCI. Mary Alice is a former teacher in the Madison County School System and is involved with several local civic organizations and garden clubs. She is an instructor of Ikebana, the art of Japanese flower arranging, and is involved with Hull Baptist Church's flower ministry.

Lisa Dawson (3) has been involved in violence prevention and unintentional injury for more than 10 years. She currently serves as the Director of the Injury Prevention Section, Environmental Health and Injury Control Branch, Division of Public Health, Department of Human Resources. Lisa is also an active participant in the Child Fatality Review; an Advisory Member for Domestic Violence Fatality Review Project; a member of the Suicide Prevention Coalition of Georgia; and a member of the Georgia SAFE KIDS Coalition. Lisa was appointed to the Commission in April 2007.

Joseph D. Frazier (4) is the President and CEO of Para/Quad Services, Inc., Essential Staffing and

Professional Services. He was appointed to the Commission by the Governor in 2007. J.D. has been the recipient of numerous honors and awards, and is the president of the Kennesaw State Alumni Association, a member of the Georgia Association of Community Care Providers, and a registered peer supporter for Shepherd Center. He speaks publicly about diversity awareness and is an advocate for disability rights.

Griffin Garner (5) was appointed to the Commission by the Governor in 2007. After serving on the staff of U.S. Senator Zell Miller in Washington, Griffin returned to his native Georgia where he has managed Governmental Affairs for the Southwire Company since 2004. He is a graduate of the University of Alabama and he and his wife, Emily, reside in Carrollton.

Gina Gelinas (6) joined the Commission in October of 2007, and serves on the Children & Youth Committee. She is the Program Manager of the Georgia Project for Assistive Technology (GPAT), a special project of the Georgia Department of Education, Division for Special Education Supports. Certified in speech-language pathology, she provides learning and technical support services to local school system personnel who work with students who need assistive technology.

Catherine Ivy (7) has worked in the field of aging and disability services for 20 years, specifically in care management, homecare, service planning, and policy development. In October 2008, she joined the Georgia Department of Community Health as Director of the Long Term Care Section, Medical Assistance Plan, where she



develops policy and oversees Georgia's long term care programs including the Medicaid waiver programs, nursing homes, community mental health services, home health, hospice services, psychiatric residential treatment facilities, and the Money Follows the Person demonstration grant. Catherine was selected to represent the Department of Community Health as its Commission appointee in October 2008.

Susan Johnson (8), Vice Chair, was appointed by the Governor in 2002. Susan is a speech language pathologist who works at the Shepherd Center as the Director of Brain Injury Services. She is a member of the American Speech and Hearing Association, and has held leadership positions at the National Brain Injury Association and the Brain Injury Association of Georgia. Susan lives in Alpharetta with her husband Mark, who is a C-5 quadriplegic and nationally-recognized advocate for people with disabilities.

Rusty Kidd (9), Chair, was appointed Chairman of the Commission by Governor Perdue in 2004. A native Georgian, Rusty consults with state and local governments on behalf of associations and businesses, ranging from the Georgia Association of Home Health Agencies to Merck. Rusty has also served on the boards of Shepherd Center and Habitat for Humanity, among others.

Steven K. Leibel (10), an attorney at Steven Leibel P.C. Trial Attorneys and Counselors at Law, is best known for winning the highest jury verdict in Georgia history and has been named a Georgia Super Lawyer for three years in a row by his peers. Steve is active in the community serving as a Municipal Court Judge in Duluth and Snellville, and sits on the boards of the Marcus Institute, Chestatee Regional Hospital, First Citizen's Bank, the NCMA Atlanta Chapter, and the Dahlonega-Lumpkin County Chamber of Commerce.

Carl H. McRae (11) serves as Director of the Vocational Rehabilitation Program at the Georgia Department of Labor. He began his career as a counselor intern at the Georgia Vocational Rehabilitation Agency while studying for a master's degree in rehabilitation counseling. Carl's longstanding interest in people with TBI has led him to develop unique and unconventional means of assessment. He also served as the first statewide program coordinator for TBI with the Georgia Division of Rehabilitation Services.

Estelle Lee Miller (12), an attorney and consultant, gained a passion for this field after her daughter, Linda Jean, experienced a traumatic brain injury. A Charter Member of the Commission, Lee was appointed by the Governor in 2000. She is active in the President's Council on the 21st Century Workforce, Skills Gap committee; the World Committee on Disability; the National Association of Governors' Councils; the Georgia State Rehabilitation Council and both the Georgia and the National Rehabilitation Associations. Lee has been honored twice for Distinguished Contributions toward the Full Employment of People with Disabilities by the President's Committee on Employment of People with Disabilities.

David W. Renz (13) was the first Chairman for the Commission, having been appointed by the Governor in 2000. David brings a wealth of personal (he has a T-8 spinal cord injury) and professional experience to the organization. He has held positions as Dalton Whitfield Disability Awareness Chair and Deacon at First Presbyterian Church.

Dan Roach (14) is the Director of Human Resources for the Georgia Department of Public Safety, where he has served since 1999. Dan joined the Commission in 2008 as the DPS representative. Dan holds a Master of Public Administration (M.P.A.) degree from Indiana University, and has more than 17 years of human resource management experience, all of which has been served in the public sector.

William "Bill" E. Smith was appointed to the Commission by Governor Perdue. A graduate of the Citadel Military College, SC, Bill has served as a special agent with the FBI, and as an officer in the United States Marine Corps. He is a member of the Woodbine Lions Club, and served three terms on the Camden County Board of Commissioners and was sheriff of Camden county for many years.

Applying for A Trust Fund Award

The Trust Fund welcomes applications from all Georgians who have sustained a traumatic brain and/or spinal cord injury.

To qualify, we ask that applicants:

- show proof of US citizenship
- show proof of Georgia residency for one year
- supply quotes for all services and goods requested
- explain how an award will increase your independence, have long-term benefits and promote inclusion in your community.

Applications are reviewed every month and we strive to respond within three months of a completed request.

We are committed to improving the quality of life for the more than 57,000 Georgians who sustain a TBI/SCI each year. So, call us (1-888-233-5760) if you are unsure about applying. We are happy to help you find the resources you need.

Four Steps to an Award

Step 1: Apply online at www.bsitf.state.ga.us or call toll-free (1-888-233-5760) for an application. As soon as your application is complete (e.g., has all supporting documents), it is sent to the Distribution Program staff.

Step 2: The Distribution Committee reviews applications and makes a recommendation for funding to the Commission.

Step 3: The Commission votes to adopt the recommendations made by the Distribution Committee, approximately six to eight weeks from the receipt of a completed application.

Step 4: The Commission sends funding recommendations to the Governor's Office for approval as required by our legislation. After receiving approval from the Governor, the Commission will notify you by letter.

Our Staff



(Left to Right): Wendy Butts, Director of Planning and Review; Stephanie Lotti, Director of Data and Public Policy; Leslie McNely, Director of Finance and Operations; Craig Young, Executive Director; Dionne Braxton, Application Associate; Dionna Littlejohn, Director of Application Management. Not pictured: Ayanna Anderson, Stewardship Coordinator.

The Commission At-A-Glance

WE HAVE POPULAR SUPPORT. In November 1998, Georgia voters overwhelmingly approved (by 73%) a constitutional amendment to create a Trust Fund for brain and spinal injuries, paid for by a surcharge on drunk driving fines. This landmark legislation won by a margin of greater than 2-to-1.

WE ARE GUIDED BY THOSE WITH FIRSTHAND KNOWLEDGE. The idea of the Trust Fund and the advocacy efforts on behalf of the founding legislation was driven by people with traumatic brain injury (TBI) and spinal cord injury (SCI). Because of their first-hand experiences, they knew what was most important for people with these traumatic injuries – and what was missing in the range of services and resources available. They dreamed of an agency that understood the lifelong needs of people with traumatic injuries and that was committed to supporting injured individuals at different stages in their life – not just in the critical moments after the injury occurs.

Additionally, more than half of the people who serve on the Commission must have a brain or spinal cord injury or be a family member of a person with an injury. Other members are specialists in the field, or work with organizations that provide services to people with traumatic injuries. Their collective knowledge and experience governs our day-to-day decisions, guides our recommendations for award distributions, and informs our public policy agenda.

WE CONNECT PEOPLE TO THEIR COMMUNITIES. Georgians with traumatic brain and spinal injuries deserve lives of independence and inclusion, lives rich with vision and possibilities. Trust Fund awards assist individuals with injuries in reaching these goals.

Trust Fund awards change lives.

The 2008 Patherfinder Award, "Jazz Combo" by artist Allen London of Atlanta. London was injured in a severe automobile crash that left him in a coma for three months. He is committed to using his talents "to do something for people that have had incidents like myself and to show what God can do."



THE MISSION of the Brain and Spinal Injury Trust Fund Commission is to enhance the lives of Georgians with traumatic brain and spinal cord injuries. Guided by the aspirations of people with traumatic injuries, the Commission supports lives of meaning, independence, and inclusion. As the state's Lead Agency on Traumatic Injuries, we:

- Administer the Central Registry to identify those who are injured,
- Distribute resources through the Trust Fund, and
- Advocate for improvements in statewide services.



Brain & Spinal Injury Trust Fund Commission 2 Peachtree Street NW, Suite 26-426 Atlanta, Georgia 30303 Phone: 404-651-5112 Fax: 404-656-9886 Toll-free: 1-888-233-5760 www.bsitf.state.ga.us

